Children with Special Needs

Internet Guide for Parents and Professionals



Delaware Department of Health & Social Services

Birth to Three Early Intervention System





This guide was produced to help parents and professionals seeking information about children with special needs gain access to the various web sites that may address needs or questions they have. The Internet is a source of information that may or may not contain valid information. Information derived from these sites does not necessarily reflect the opinions or practices of anyone involved with the Birth to Three Early Intervention System. This guide serves as a resource only, not as an endorsement or validation for the information provided by the site. Information provided by the sites should not be construed as medical advice. Please consult your health care professional before making any decisions regarding your child's health care needs.

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Basic Internet Directions:

- When you begin a search on the Internet, there are many search engines that can be used to search for a topic of choice. A search engine is a webpage database that gives an option to search for various topics. Each differs in the way the results of the search are displayed. Any search engine may be used depending upon the personal preference of the searcher, and you may find different sites located in each engine. You may also find that the search results of one day may be different then a previous day due to the many changes that occur on the Internet from day to day.
- Below are listings of search engines and websites that may be useful to you as you begin your search. The way that these engines and sites can be found is to do the following:
 - When you begin use of the Internet, you will be on a main page that will be a search engine of its own. It could be any one, dependent on the server that that is used. For example, this could be America on-line, Netscape, AT&T, etc.
 - 2. If you want to search from this screen, simply go to the search box and enter the keywords of the topic of interest. Results will be displayed and you will be able to choose the topic or site of your choice. You will be able to return to that search site from the new site that you go to by clicking on the back square at the top of the screen.
 - 3. If this search engine is not what you want to use, find the long box at the top of the screen where the word 'address' is located. From here click once on the website address, for example http://www.yahoo.com. Doing this will turn it blue in color and then by hitting backspace it will be erased. A double click on this will allow you to have a cursor in the address box and from there you can blackout any part of it you wish.
 - 4. When it is blank, you may enter a new address that should always start with: http:// Sometimes you will need the www after this, and other times it is not needed (it should be entered if it is written that way on this sheet).
 - 5. When you are finished typing in the entire address, press 'enter' and the computer will search for the website of your request.
 - 6. If an error message is given, check the address and re-enter. Sometimes the server for the site is down and it may be advisable to try again another time.

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Below are the addresses for some search engines and websites that may be helpful to you. Good Luck and enjoy surfing the Web.

Search Engines

Alta Vista	altavista.digital.com/cgi-bin/query	
Amazon	amazon.com	
Excite	www.excite.com/index.html	
Go	go.com	
I find	m5.inference.com/ifind/	
Lycos	www.lycos.com	
Meta Crawler	Metacrawler.com	
Savvy Search	www.search.com	
Snap	snap.com	
Web Crawler	www.webcrawler.com	
Yahoo	www.yahoo.com	

Medline Search (Medical search engines)

Health Gate Medline Access	www.healthgate.com
Health World Medline Access	www.healthy.net/library/search/medline.htm
Medscape	www.medscape.com/

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Government

Federal Register - U.S. Department of Education Announcement	www.Ed.Gov/Legislation/Fed Register/	Provides a choice of the U.S. Department of Education documents to be viewed.
Federal World Home Page	www.fedworld.gov/#hletr	Provides a way to search within the government for reports and information
GPO Access	www.access.gpo.gov/su_docs /db2.html	Provides a link to search different departments of government
HHS Agencies	www.hhs.gov/agencies	Home page for the office of Health and Human Services
I DEA Practices	www.ideapractices.org	Resource rich and highly interactive website that provides service providers and local administrators with information and support for I DEA-related concerns, issues, and strategies; also provides links
Social Security Online	www.ssa.gov	Provides information about social security
U.S. Dept of Education	www.ed.gov	Home page for the U.S. Department of Education
U.S. Federal Government Agencies	www.lib.lsu.edu/gov/fedgov. Html	U.S. Federal Government agencies directory

Laws concerning Disability

Americans with	handicap.bfn.org/public/ada.	Library directory of topics on the
Disabilities Act (ADA)	html	Americans with Disabilities Act
Laws Affecting Children with Special Needs	www.lrp.com/Fed.htm	Site comprised of a listing of materials and directories around
·		issues of law available for order
National Center for	www.ncddr.org/index.html	Provides information on research in
Dissemination of		the area of children with disabilities
Disability		and collaboration between federal
Research(NCDDR)		agencies
Office of Civil Rights -	www.ed.gov/offices/OCR	Homepage for the Office of Civil
Department of Education		Rights that provides information on
		the law, recent publications, and links
		to related sites

The Consortium for	www.c-c-d.org	Homepage that discusses the
Citizens with		organization and provides information
Disabilities (CCD)		on recent news about disabilities
I DEA '97	www.ed.gov/offices/OSERS/	Provides information on the Individuals
	I DEA/index.html	with Disabilities Education Act

Finance Issues

Health Care Financing Administration (HCFA)	www.hcfa.gov	Information on Medicare, Medicaid, and Child Health insurance
Social Security Benefits for Children with Disabilities	ftp://ftp.ssa.gov/pub/pubs/ 10026.html	Article discussing social security benefits for children with disabilities (government publication)
The Finance Project	www.financeproject.org	National initiative to create knowledge and share information that will lead to the improved well-being of children, families, and communities

Early Intervention/Early Childhood

Child Development Media,	www.childdevmedia.com	Provides a listing of videos and training
Inc.		materials produced by leading behavior
		specialists, available for purchase
Division of Early	www.dec-sped.org	Provides information on conference,
Childhood		government actions, links, and
		publications
Early Intervention	www.dec-	Links to sites related to Early
Related Links	sped.org/eilinks.html	Intervention, children with special
		needs and their families. Information
		dealing with policy, research, and
		services included
I.E.P	www.ldonline	Provides information about the
	go to Search and type in	Individualized Education Plan and what
	"I EP"	they mean to the family and child-
		This also discusses a lot about learning
		disabilities
The Hanen Early	www.hanen.org	Provides information about the
Language Program		program concerning language delay and
		updates of research- Also provides
		links and materials available for
		purchase

Transition

Allen, Shea, and Associates	www.allenshea.com	Professional services in the area of planning, research, training, materials development, and evaluation within the field of human services emphasizing developmental disabilities
FACTS/LRE Project	facts.crc.uiuc.edu/facts4/ facts4.html	Planning your child's transition to preschool – step by step guide for families
Preparing Children with Disabilities for School	kidsource.com Go to search type in "transiton for children with disabilities"	Article with information on how government supports readiness, special problems faced during transition, family role, teacher's role, elements of successful transition, transition timeline

Advocacy

ARC of the US	www.thearc.org	National organization of and for people with mental retardation and related disabilities and their families; resources, publications, FAQ's, and links
Children Now	www.childrennow.org	Group working to advocate for children and families. Provides information about the organization, articles, resources, newsletter, and links to other resources
Children's Defense Fund (CDF)	www.childrensdefense.org	Provides valuable information about the children's population in the U.S. and articles on several issues, also a Parent Resource Network
Family USA Foundation: The Voice for Health Care Consumers	www.familiesusa.org	Provides information about the organization, publications, and child health
Family Voices	www.familyvoices.org	Provides information sheets, publications, resources, and listing of their current projects; also available in Spanish
National Association of Protection and Advocacy Systems (NAPAS)	www.protectionandadvocacy.	Contains references to training, material, and resources of value to disability advocacy organizations

Parent & Family: Information and Support

Baby Place: The internet Parenting Resource	www.baby-place.com	Provides information on pregnancy and birth, parenting, products and services, and general parent concerns
Beginnings for Parents of Children who are Hard of Hearing	beginningssvcs.com	Help parents be informed, empowered, and competent so they can be knowledgeable decision makers
Children's Liver Alliance	www.livertx.org	Provides link to CenterSpan support site for parents dealing with transplants
Chromosome Deletion Outreach	Chromodisorder.org/index. html	Support group for families dealing with children with chromosome concerns
Contact Information	www.seliger.com	Provides grant writing services
Dictionary: For Parents of Children with Disabilities	www.usd.edu/sduap/Dictiona ry/Dictionary.htm	Comprehensive dictionary of terms pertaining to children with disabilities
Family Internet Home Page	www.familyinternet.com	Provides information on many areas for families and individuals in general
Family Support Network of NC Home Page	Fsnnc.med.unc.edu	Organization based out of North Carolina that provides a directory of services, camp listings and links
Our Kids	www.our-kids.org	Site dedicated to raising children with special needs
Parent News	www.parent.net	Provides facts, articles, movies, resources, and books
Parent's Rights and Responsibilities	www.accesseric.org/ resources/parent/ disab1.html	Parent Brochure - Rights and Responsibilities of parents of children with disabilities
Parents Place	www.parentsplace.com	Discusses pregnancy, health, family, work, and chat is available
Reference Circular Parents' Guide to the Development of Preschool Children with Disabilities: Resources & Services	www.loc.gov/nls/reference/ circulars/parents.html	Wide range of information to assist in promoting the development of a child with disabilities from infancy to age 5. Listing of organizations, producers, and distributors who offer materials or services, also a listing of books
Special Child Magazine	www.specialchild.com/ index.html	Online publication dedicated to parents of children with special needs

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Sibling Relationships

Children with Disabilities:	Ldonline.org	Article on sibling issues
Understanding Sibling	Go to search and type in	
Issues (NICHY)	"siblings"	
Kids N' Sibs	www.ggw.org/freenet/k/kns/	Provides an online newsletter for
	index.html	siblings of children with disabilities,
		off-line newsletter also available
The Sibling Support	www.chmc.org/departmt/	Provides general information for
Project	sibsupp	siblings of all ages of children with
		special needs, resources, newsletter,
		information on sibshops

Technology

Alliance for Technology Access	www.ataccess.org	Provides information on assistive technology centers, books, facts, and vendors
Applied Science and Engineering Labs	www.asel.udel.edu	Gives information on terms, devices, and types of equipment, also links to other resources
Assistive Technology devices and Services	interact.uoregon.edu/wrrc/ IDEAATech.html	Information on IDEA amendments affecting assistive technology
Center for Computer Assistance to the Disabled	www.c-cad.org	Provides information on the organization and topics on computer assistance, information, referral, and links available
Delaware Assistive Technology Initiative (DATI)	www.asel.udel.edu/dati	Discusses assistive technology help for people and children in Delaware, newsletter available

Adaptive Toys

www.adaptivemall.com	Assistive technology and adaptive
	devices at discount for children and
	youth with disabilities; full line of toys
	and games as well as many other
	categories of assistive devices
www.familyvillage.wisc.edu/at	Provides a listing of resources and
/adaptive-toys.html#info	vendors surrounding adaptive toys
, ,	
	www.familyvillage.wisc.edu/at

Kaplan	www.kaplanco.com	Building activities, game boards, balloon kits, balls, etc. Four categories to choose catalogs from: exceptional children, early childhood, outdoor classroom, and math, science, technology & more
TFH (USA) LTD	www.tfhusa.com	Line of unique, adapted toys and products for children and adults with special needs
The Dragonfly Toy Company	www.dragonflytoys.com	For children with special play needs; online catalog and tips

Adaptive Clothing

Family Village - Adaptive	www.familyvillage.wisc.edu/at	Provides vendor listings and other
Clothing	/adaptive-clothing.htm	resources surrounding adaptive
		clothing
Special Clothes, Inc.	www.special-clothes.com	Adaptive clothing for children with
	·	disabilities, helping boys and girls with
		special needs meet the world with
		pride and confidence

Adaptive Equipment

Enabling Devices	www.enablingdevices.com	Exceptional Products for Exceptional People
		reopie
Flaghouse	FlagHouse.com	Provides a one-stop shopping experience
Haverich	www.haverich.com	Wide variety of Orthopaedic Cycles
Mealtimes	www.new-vis.com	A resource for oral-motor, feeding, and
		mealtime programs

Activities

Alternative Leisure	www.alctrips.com	Provides information about trips and
Company		camps for children with disabilities
Special Olympics	www.specialolympics.org	Program of sports training and competition for individuals with mental retardation
The American Camping	soarch acacamps arg/soarch	Provides a way to search the country
The American Camping	search.acacamps.org/search.	for camps according to need
Association	html	Tor camps according to need

Entertainment

Disability Center	www.disabilitycentral.com/ activeteen	DC Active teen is managed by and for teens with disabilities. We are an online cyber community where we can socialize, educate one another and just have fun together.
Lycoszone	Lycoszone.Lycos.com	Light-hearted website that focuses on youngsters and teens.

National Disability Organizations

American Association of University Affiliated Programs for Persons with Developmental Disabilities	www.aauap.org	Provides information about organizations for people with disabilities, legislation, special projects, resources, membership, and links
American Association on Mental Retardation	www.aamr.org	Provides information on careers, publications, conferences, etc.
American Society for Deaf Children	www.deafchildren.org	Providing a link between those with experiences to share and people seeking answers; services, resources, and links
American Speech- Language-Hearing Association	www.asha.org	Provides information for professionals, students, and consumers
ARC of the US	www.thearc.org	National organization of and for people with mental retardation and related disabilities and their families; resources, publications, FAQ's, and links
Association of Birth Defect Children, Inc.	www.birthdefects.org	National clearinghouse to provide parents and professionals with information about birth defects and services for children with disabilities
Council for Exceptional Children	www.cec.sped.org	Provides information about membership, legislation, publications, etc.
Federation of Families for Children's Mental Health	www.ffcmh.org	National parent-run organization focused on the needs of children and youth with emotional, behavioral, or mental disorders and their families
National Academy for Child Development	www.nacd.org	International organization of parents and professionals dedicated to helping

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		T
		children and adults reach their full
		potential. Articles, research,
		resources, products, and programs
National Alliance for the	www.nami.org	Leading advocacy organization
Mentally I II		dedicated to improving the lives of
		persons with severe mental illnesses
		and severe anxiety disorders
National Association for	www.naeyc.org	Nation's largest organization of early
the Education of Young	, ,	childhood professionals and others
Children (NAEYC)		dedicated to improving the quality of
Children (IVAL 10)		early childhood education programs
		for children birth through age eight
National Council on	www.ncd.gov	Independent federal agency making
	www.nea.gov	recommendations to the President and
Disability		Congress on issues affecting 54 million
		Americans with disabilities
National Custic Fibracia	www.off.org	
National Cystic Fibrosis	www.cff.org	Resource of information on Cystic
Foundation		Fibrosis; research, facts, publications,
		and news
National Early Childhood	www.nectas.unc.edu	National Technical Consortium working
Technical Assistance		to support states, jurisdictions, and
System		others to improve services and results
		for young children with disabilities and
		their families
National Easter Seal	www.seals.org	Non-profit, community-based health
Society		agency dedicated to helping children
-		and adults with disabilities attain
		greater independence
National Health	nhic-nt.health.org	Health information referral service
Information Center		
National Information	www.nichcy.org	National information and referral
Center for Child and	www.meney.erg	center that provides information on
		disabilities and disability-related
Youth with		issues for families, educators, and
Disabilities(NI CHCY)		other professionals, available in
		Spanish
National Institute of	www.nimh.nih.gov	Mental health research organization;
	vvvvv.iiiiiiiiiiiiigov	valuable information on specific mental
Mental Health		·
		disorders, diagnosis, and treatment
Nietienell		(also in Spanish)
National Institute on	www.ed.gov/offices/OSERS/	Provides leadership and support for a
Disability &	NI DRR	comprehensive program of research
Rehabilitation Research		related to the rehabilitation of
		individuals with disabilities

National Mental Health Association	www.nmha.org	Dedicated to improving the mental health of all individuals and achieving victory over mental illnesses
National Organization of Parents of Blind Children	www.nfb.org	Organization of parents and friends of blind children reaching out to each other to give vital support, encouragement, and information
National Organization on Disability	www.nod.org	Only National disability organization concerned with all disabilities, all age groups, and all disability issues
National Parent Network on Disabilities	www.npnd.org	Provide a presence and national voice for ALL families of children, youth and adults with disabilities
National Transition Alliance for Youth with Disabilities (NTA)	www.dssc.org/nta/html/ index_2.htm	Promotes the transition of youth with disabilities toward desired post-school experiences, including gainful employment, post-secondary education and training, and independent living
Office of Special Education & Rehabilitation Services (OSERS)	www.ed.gov/offices/OSERS	Supports programs that assist in educating children with special needs, provides for the rehabilitation of youth and adults with disabilities, and supports research to improve the lives of individuals with disabilities
Office of Special Education Programs (OSEP)	www.ed.gov/offices/OSERS/ OSEP/index.html	Their mission and organization focus is on the free appropriate public education of children and youth with disabilities from birth through age 21
Research & Training Center on Family Support & Child Mental Health	www.rtc.pdx.edu	Activities focus on improving services to families whose children have mental, emotional or behavioral disorders through a set of related research and training programs

General Disability Sites

Equal Access to Software	www.isc.rit.edu/~easi	Serves as a resource to the education
and Information		community by providing information in
		the area of access to information
		technologies by individuals with
		disabilities; on-line seminars and
		workshops

Cornucopia of Disability Information (CODI)	codi.buffalo.edu	Information on disabilities including statistics, directories, databases, etc.
Internet Resources for Special Children	www.irsc.org	Provides links to the internet about disability areas
MCH-NetLink Project	www.ichp.edu	Monthly electronic newsletter on Maternal Child Health Community
Nemours	www.nemours.org/no	One of the nation's largest pediatric subspecialty group practices. Provides
	www.kidshealth.org	information and resources for a wide range of children's health and disability issues.
Self-Help Source Book	www.cmhc.com	Provides a directory of support groups and networks that are available throughout the world and in your community
The ARC's Q&A on Respite Care	www.thearc.org/faqs/respite .html	Information on respite care
The Family Village	www.familyvillage.wisc.edu/index.htmlx	Global community that integrates information, resources, and communication opportunities on the Internet for persons with disabilities, their families, and those who provide them service and support
The JP Das Developmental Disabilities Centre	www.quasar.ualberta.ca/ddc/INDEX.html	Containing valuable information and resources in five major areas: inclusive education, violence & disability, developmental disabilities, human ethics, and links by categories; for parents of children with developmental disabilities
Zero to Three: National Center for Infants, Toddlers, & Families	www.zerotothree.org	Goal is to strengthen and support families, practitioners, and communities to promote the healthy development of babies and toddlers;

Specific Disability Sites:

ADD/ADHD

A.D.D	www.cpgs.com/add	Treatment and Research Center
A.D.D. Clinic	www.addclinic.com	Diagnosis and treatment of Attention Deficit Disorder
ADD (C.H.A.D.D.)	www.chadd.org	Works to improve the lives of those with ADD/ADHD through education, support, and advocacy
ADD & Oppositional Defiant Disorders in Children & Adults	users.choice.net/~digital/ index.htm	Article on this issue, and links
ADD/ADHD	www.sinbad.net/business/adds	Important information regarding the side effects of common medications
ADD/ADHD support group	www.adders.org	Online support group, also provides news, information, research, resources, and links
Feingold Association of the United States (FAUS)	www.feingold.org	Dedicated to increasing awareness of the connection between diet and the symptoms of ADD, ADHD, and learning disabilities
National Attention Deficit Association (ADDA)	www.add.org	Organization that seeks to help people with ADD lead happier, more successful lives through education, research, and public advocacy
Resources on ADD	teis.virginia.edu:0080/go/cise/ose/categories/add.html	Resources and information on ADD from the office of Special Education
Ritalin, ADHD, and Diagnosing Children	www.breggin.com/ritalin.html	Articles through the Center of Psychiatry and Psychology

<u>Autism</u>

AACAP	www.aacap.org/publications/	Article on the autistic child
	factsfam/autistic.htm	

Autism Network for	www.autismndi.com	Providing help and support for
Dietary Intervention	www.dutiSiiiidi.com	families using a Gluten & Casein Free
Dietary Triter vention		Diet in the treatment of autism and
		related developmental disabilities
Autism Resources	www.vaporia.com/autism	Information and index of links
, lation resources	www.vaporia.oom, auciom	regarding the developmental
		disabilities autism and Asperger's
		Syndrome
Autism Resources in the	www.autism-info.com	Site providing information on
U.S.A.		national organizations, resources,
C.C., t.		and research throughout the United
		States. Selection of state can be
		made
Autism Society of	www.autism-society.org	Mission is to promote lifelong access
America	g	and opportunities for persons within
7 tiller led		the autism spectrum and their
		families, to be fully included,
		participating members of their
		communities through advocacy,
		public awareness, education, and
		research related to autism
Autism Support &	members.xoom.com/viah	Created by a group of autistic
Information		adults- Provides information and
		support
Autism Videos	www.autism.com/cont_ed_prog	Provides information on videos for
	, ,	sale
Autism-PDD (Pervasive	autism-pdd.net	Information guide dedicated to
Developmental Disorder)		autism spectrum disorders
Network		
Center for Study of	www.autism.org	The Center provides information
Autism (CFA)		about autism to parents and
Addisin (Ol 71)		professionals, and conducts research
		on the efficacy of various
		therapeutic interventions. Much
		research is in collaboration with the
		Autism Research Institute in San
		Diego, California.
Community Services for	www.csaac.org	Private, non-profit organization that
Autistic Adults &		offers services to individuals with
Children (CSAAC)		autism
Cure Autism Now (CAN)	canfoundation.org	Dedicated to promoting and funding
(a, a, a	Jan. Jan. Gar. Gar. Gar. Gar. Gar. Gar. Gar. Gar	research with direct clinical
		application for treatment of autism
FEAT	+	1 1
	rdrop.com/users/feator	Families for Early Autism Treatment
ILAI	rdrop.com/users/feator	Families for Early Autism Treatment of Oregon providing resources, links,

Future Horizons	www.futurehorizons-autism.com	Provides information on videos, books, publications, and conferences; links and newsletter
other sites	www.autism.org/links.html	List of internet resources and links concerning autism
TEACCH	www.unc.edu/depts/teacch	Treatment and education of autistic and related communication handicapped children
The Autism Channel	www.autismchannel.net	Provides chat, information, and support to parents with children with autism or related disorders
The Autism Society of Delaware	www.wserv.com/delautism	Families and friends of people with autism providing education, advocacy, and public awareness throughout Delaware

Asperger's Syndrome

ASPEN - Asperger Syndrome Education Network, Inc.	www.aspennj.org	Education about issues, support, and advocacy
ASPEN of America	www.asperger.org	Provides support and information to parents of children with Asperger's and related disorders
Asperger's Syndrome	www.wpi.edu/~trek/aspergers.ht ml	Information about the disorder, internet resources and support networks, and reading lists
Asperger's Syndrome	www.autism-society.org go to search and type in "asperger's syndrome"	Answers to frequently asked questions, resource list
Disorder Homepage	www.ummed.edu/pub/o/ ozbayrak/asperger.html	Provides general information on Asperger's syndrome
OASIS	www.udel.edu/bkirby/ asperger	On-line Asperger's syndrome Information and Support
Welcome to A.S.P.I.E. Asperger's Syndrome Parent Information Environment	Aspie.freeservers.com/index. html	Provide support and information, share personal experiences

Bone Disorders

Fibrous Dysplasia	www.methodisthealth.com/	Information about the disease
	use search engine "A to Z"	
Osteogenesis I mperfecta	www.healthlinkusa.com/	Links to websites which may include
	231.html	treatment, cures, diagnosis,
		prevention, support groups, risk
		factors, research, and more
Osteogenesis Imperfecta	www.oif.org	General information, links, and
Foundation		support; Free subscription to
		newsletter

Brain Injury

Brain Injury Association, Inc.	www.biausa.org/index.htm	Comprehensive web site for persons with brain injury and their families; state offices, resources in various media, treatment and rehabilitation, National Directory
Brain Injury Center	www.braincenter.org	An information gateway regarding acquired brain injury
Brain I njury Guide	members.aol.com/bigkate4/ big.htm	Personal page providing information, story, and links
Brain Injury Information Network	tbinet.org	Statistics, coma information, email support groups, resources and links
Brain-Net	www.btinternet.com/~brain. net/	International Consultancy in child development; U.K. site about brain injury available in English, Dutch, and I talian
Coma Waiting Place	www.waiting.com	Directed to those who are waiting while someone is in a coma, information about brain injury, resources, and support
The Perspectives Network (TPN)	www.tbi.org	Focuses to communicate public awareness and knowledge of acquired brain injury
Traumatic Brain Injury Model Systems	www.tbims.org	Links to publications, a database, news, the center for outcomes measurement, and other areas

Cerebral Palsy

CP: Resource Center	www.twinenterprises.com	Provides answers to FAQ's, a book
		list, and resources
Cerebral Palsy	www.comeunity.com	In children: articles and resources
_		for parents
How Can I Help?	www.iinet.com.au/~scarffam/cpa.	Information for friends and relatives
	<u>html</u>	of a child with cerebral palsy
NI CHCY- General	www.kidsource.com/NICHCY/	General information about Cerebral
Information about	cerebral_palsy.html	Palsy including definition, incidence,
Cerebral Palsy		characteristics, educational
		implications; and a list of resources
		and organizations
United Cerebral Palsy	www.ucpa.org	Seeks to advance the independence,
Association (UCPA)		productivity and full citizenship of
		people with cerebral palsy and other
		disabilities
What is CP?	abone.superonline.com/cpalsy	Informative site in English and
		Turkish about cerebral palsy

Cleft Lip & Palate

Cleft Lip and Palate	www.plasticsurgery.org/	Plastic surgery information
Surgery	surgery/cleftlp.htm	
Cleft Lip and/or Palate	www.craniofacial.net	General information, as well as
Deformities		information on surgery, feeding,
		problem with ears, speech evaluation
		and treatment
Cleft Lip/Cleft Palate	www.surgery.uiowa.edu/	Brief tutorial from the University of
	surgery/plastic/cleftnet.html	I owa's Department of Plastic Surgery
Cleft Lip/Cleft Palate:	www.samizdat.com/#cleft	List of articles with links
Internet Resources		
FAQ: Cleft Lip/Palate	www.plasticsurgery.org/faq/	FAQ's about cleft plastic surgery
	cleft.htm	
International Institute	www.cleft.net/info	Information, support, research, and
for Birth Defects		prevention on Cleft Lip/Palate
Wide Smiles	www.widesmiles.org	Support, inspiration, information, and
		networking for families dealing with
		the challenges associated with
		clefting

Cystic Fibrosis

CF.com	www.cysticfibrosis.com	Provides support, resources, and
		information
Cystic Fibrosis –	www.pslgroup.com/CF.htm	The latest medical news and
Doctor's Guide to the		information for patients or
Internet		friends/parents of patients
		diagnosed with Cystic Fibrosis and
		related disorders
Cystic Fibrosis Care	www.cfcare.com	Provides people with cystic fibrosis,
		family members, and the CF
		community with quick and easy access
		to education, information, and
		breaking stories on the latest
		treatments and issues
Cystic Fibrosis	www.cff.org	Resource of information
Foundation		
Cystic Fibrosis Index of	Vmsb.csd.mu.edu/~5418lukasr/	An exhaustive guide to all on-line web
Online Resources	cystic.html	pages, news groups, FAQ's, chat
		rooms, and mailing list
Cystic Fibrosis	www.cfri.org	Information on research in the field
Research, Inc.		
Cystic Fibrosis Web	cf-web.mit.edu	Information, links, support groups,
		and publications
Family Guide to Cystic	www.phd.msu.edu/cf/fam.html	Basic information for families
Fibrosis Genetic Testing		

Deaf/Blind

American Association of	www.tr.wosc.osshe.edu	National consumer advocacy
the Deaf-Blind		organization for people who have
		combined hearing and vision
		impairments
Deaf/Blind Online	www.ssco.esu.k12.oh.us/	Provides technical assistance to
	deafblind.html	families, educational personnel, and
		other service providers through
		training efforts and the
		dissemination of information on
		innovative approaches to educating
		children and youth with dual-sensory
		impairments

Helen Keller National	www.helenkeller.org/national	Provides state resources, links, and publications
Center for Deaf/Blind		publications
Youth		
National Information	www.tr.wosc.osshe.edu/dblink	Provides links, state resources,
Clearinghouse on		databases, and publications
Children who are		
Deaf/Blind		
National Technical	www.tr.wosc.osshe.edu/ntac	Provides statistics and workshop
Assistance Consortium		information
for Deaf/Blind		

Down Syndrome

Assoc. for Children with	www.acds.org	Provides facts, support, and
Down Syndrome(ACDS)		resources
Breastfeeding a Child	home.vicnet.net.au/~nmaa/	Information on this subject
with Down Syndrome	bfinfo/down.html	
Diagnosis Down	Leeworks.net/DDS	Personal site with stories dedicated
Syndrome		to parents
Down Syndrome Health	www.ds-health.com	Provides essays about children with
Issues		down syndrome for other parents
		written by a pediatrician and father
Down Syndrome Online	www.dsoag.com	Scientific and educational effort
Advocacy Group		aimed at utilizing the communication
		power of the Internet to increase
		public understanding and support for
		clinical and biomedical research into
D C 1 140404/	/ /	Down syndrome
Down Syndrome WWW	nas.com/downsyn	English, Spanish, and French speaking
page		site that provides articles, essays, snapshots, links, information, and
		resources
Down Syndrome: Health	www.ds-health.com	Articles, information lists, links and
Issues		abstracts
Down Syndrome-A	www3.sympatico.ca/terry.	Parent site with personal stories,
Parents Resource	edwards/Shelby.html	photos, and resources
DownsCity	www.downscity.com	Provides a directory, mailing lists,
-	-	resources, and links
DownsNet	www.downsnet.org	Contains information on research, a
		library, and services on Down
		Syndrome

Growth Charts for Children with Down Syndrome	www.growthcharts.com/ charts/DS/charts.htm	Growth charts for children with Down Syndrome
National Association of Down Syndrome	nads.org	Not-for-profit organization providing information and understanding
National Down Syndrome Congress	members.carol.net/~ndsc/index_fr.html	National advocacy group that provides leadership in all areas related to persons with down syndrome
National Down Syndrome Education and Research Institute	web.idirect.com/~ndseri	I nstructional videos available and links
National Down Syndrome Society	www.ndss.org	Assists families in addressing needs of children born with down syndrome and sponsors and encourages scientific research
Recommended Down Syndrome Sites	www.ds-health.com/ ds_sites.htm#natl	Links to internet sites
The Family Empowerment Network	Downsyndrome.com	Includes government resources, educational resources, medical information and resources, support groups, newsletters, and valuable links
The Lighter Side of Down Syndrome	www.geocities.com/Heartland/ Hills/3153/dsmain.html	Personal site with stories and resources
Trisomy 21 Foundation	www.geocities.com/HotSprings/9438/index.htm	Facts, information, Truths & Myths, research, and links
UPSI DE	www.telebyte.net/upside/ upside.html	Informal society of individuals, parents, and friends

Dwarfism

Dwarfism.org	www.dwarfism.org	Centralized dwarfism resources
Human Growth	www.hgfound.org	Helps individuals with growth related
Foundation		disabilities, their families, and health care
		professionals by providing education,
		research, and advocacy
Little People of America	www.lpaonline.org	Provides support and information to people
-		of short stature and their families.
		Resources, data, and links

Fetal Alcohol Syndrome

Alcohol Related Birth Injury - Fetal Alcohol Syndrome	www.arbi.org	Offers educational research and legal resources for the prevention and treatment of alcohol-related birth injuries
Fetal Alcohol Syndrome	www.come-over.to/FAS	Provides a wide range of information including resources and links
Fetal Alcohol Syndrome Family Resource Institute - FAS	www.accessone.com/~delindam/	Non Profit Organization offers support groups, prevention programs, and information about this condition. Membership details included
MEL: Fetal Alcohol Syndrome	Mel.lib.mi.us/health/health- fas.html	Provides general information, support network, FASLI NK and a mailing list for people interested in FAS
National Organization on Fetal Alcohol Syndrome	www.nofas.org	General information of FAS

Fragile X

FRAXA Research	www.fraxa.org	Provides current information and links
Foundation		
National Fragile X	www.nfxf.org	Gives general information, resources for
Foundation		families, and links

Genetic Disorders and Birth Defects

Association of Birth Defect Children, Inc (ABDC)	www.birthdefects.org	Provides free phone information, written materials, special reports and newsletters to parents and professionals
CVS Birth Defects Registry	neuro-www3.mgh.harvard. edu/cvs/cvs.html	General information and support
March of Dimes Birth Defect Foundation	www.modimes.org	Organization that focuses on the birth of healthy babies
The Genetic Alliance	www.geneticalliance.org	Find a support group, useful resources, newsletters, and publications
The Teratology Society	www.teratology.org	Site that provides information on birth defects, research, and prevention
Ultrasound and other Prenatal Diagnostic	www.stanford.edu/~holbrook	Information on testing procedures
Tests		

Hearing Impairments

Alexander Graham Bell Assoc. for the Deaf	www.agbell.org	Nonprofit membership organization that was established in 1890 to empower persons who are hearing impaired; information, provider & support network
American Speech- Language-Hearing Association (ASHA)	www.asha.org	Promote interests of and provide the highest quality services for professionals in audiology, speechlanguage pathology, and speech and hearing science, and to advocate for people with communication disabilities
Captioned Films/Videos Program	www.cfv.org	Provides open-captioned films and videos, free for loan, for deaf and hard-of -hearing persons, teachers, organizations, and parents
Closed Captioning Web	www.captions.org	Information on closed captioning services, law and links
Hand Speak: A sign language dictionary online	www.handspeak.com	Visual language dictionary online.
I See What You Say	www.lipreading.com	Concerned with speech-reading skills, video with manual available
National Association of the Deaf	www.nad.org	Safeguards the accessibility and civil rights of 28 million deaf and hard of hearing Americans in a variety of areas
National Institute on Deaf & other Communication Disorders (NI DCD)	www.nih.gov go to search and type in "NI DCD"	Mission is to uncover new knowledge that will lead to better health for everyone- Provides information on current research
Phonic Ear	www.phonicear.com	Leading developer and manufacturer of assistive listening devices, products, tools, and links
The Deaf Resource Library	www.deaflibrary.org	Collection of reference material and links to educate and inform people about deaf cultures in Japan and the U.S.
Where do we go from Hear?	www.gohear.org/index.html	Provides information for families of infants and children diagnosed with hearing loss and professionals who work with these individuals

Hydrocephalus & Spina Bifida

Children with Spina Bifida	www.waisman.wisc.edu/ ~rowley/sb-kids/index.htmlx	Resource page for parents
Hydrocephalus Association	www.HydroAssoc.org	Provides support, education, resources, and advocacy
Hydrocephalus Center	www.patientcenters.com	Provides articles and resources
Spina Bifida Association	www.sbaa.org	Provides toll free information & referral
of America		services, newsletter, publications, and
		links
The Hydrocephalus	www.hydrocephalus.org	Dedicated to providing support,
Foundation, Inc. (HyFI)		resources, and networking opportunities
Welcoming Babies with	Reseau.chebucto.ns.ca/Health	General information about Spina Bifida,
Spina Bifida	/SBANS/welcoming.html	resources, recommended readings

Hyperlexia

American Hyperlexia	www.hyperlexia.org	Provides basic information and links
Association Home Page		
Hyperlexia and Language	www.geocities.com/	Provides articles and links
Disorders	HotSprings/9402/	
Hyperlexia Parents Page	Westwingpublishing.com/	Information for parents with personal
	hyperlexia	stories, articles, and chat available

Juvenile Diabetes

Juvenile Diabetes	www.jdf.org	Research, publications, chapters, and
Foundation International		advocacy
- The Diabetes Research		
Foundation		
National Institute of	www.niddk.nih.gov	Information on health, programs,
National Institute of Diabetes and Digestive	www.niddk.nih.gov	Information on health, programs, research, and FAQ's
	www.niddk.nih.gov	. •

Language/Speech Disorders

American Speech-	www.asha.org	Promotes interest of services for
Language-Hearing-		professionals and people advocating for
Association (ASHA)		people with communication disorders
Apraxia Kids	www.apraxia-	Provides information and how apraxia
	kids.org/index.html	affects families and children, links and
		support groups
KidsEars	www.kidsears.com/mainmenu.	Provides listing of milestones and
	htm	suggestions
Kidsource Online: Spoken	www.kidsource.com/LDA/	Basic explanation of oral language
Language Problems	spoken_language.html	disorders
National Aphasia	www.aphasia.org	Promotes public education, research,
Association		rehabilitation and support services to
		assist families
Speech and Language	www.mankato.msus.edu/dept/	Provides listing of sites related to
Disorder	comdis/kuster2/splang.html	speech and language disorders

Learning Disabilities

Essential Learning	www.rsts.net/eli/index.html	Information on LD with audio introduction option
Institute		·
LD Online	www.ldonline.org/index.html	Interactive guide to learning
		disabilities for parents, teachers, and
		children
Learning Disabilities	www.ldanatl.org	Dedicated to enhancing quality of life,
Association of America		alleviating restricting effects, and
		supporting endeavors to determine
		causes of learning disabilities
Learning Disabilities	www.ldclinic.com	Private educational treatment facility
Clinic		for children, adolescents, and adults,
		dedicated to helping individuals achieve
		their full learning potential.
National Center for	www.ncld.org	Provides information, resources,
Learning Disabilities		referral services, public awareness,
3		advocacy and more
Special Kids	www.specialkids1.com	Reaching and teaching kids with
		disabilities through videos, CD-Roms,
		and picture books
The Learning Center	learningcenteronline.com	Information about testing and
		enrichment; Educational and counseling
		services to children and adults

Leukodystrophy

United Leukodystrophy	www.ulf.org	Dedicated to providing patients and
Foundation		their families with information and
		support, increasing public awareness,
		and promoting and supporting research

Lowe Syndrome

Lowe Syndrome	www.lowesyndrome.org	Basic information and links
Association		

Mental Retardation

American Association on Mental Retardation	www.aamr.org	Promotes global development and dissemination of progressive policies, sound research, effective practices, and universal human rights for people with
		intellectual disabilities
Best Buddies	www.bestbuddies.org	A nonprofit organization dedicated to
		enhancing the lives of people with mental
		retardation by providing opportunities
		for socialization and employment
Mental Retardation and	members.aol.com/MRandDD/	Provides information on history, news,
Developmental	index.htm	movies, and links
Disabilities		
The ARC	www.thearc.org	Organization committed to the welfare
		of all children and adults with mental
		retardation and their families

Muscular Dystrophy

Muscular Dystrophy Association	www.mdausa.org	Information on research, services, publications, and clinics
Muscular Dystrophy Family Foundation	www.mdff.org	Provides services, resources, home medical equipment and adaptive devices to help people with muscular dystrophy and their family members live independent and productive lives

Muscular Dystrophy	www.parentdmd.org	Provides a network of communications,
Parent Project		support for parents and children, and
		information on the disease, treatment,
		care, and conferences

Paralysis and Spinal Cord Injury

American Paralysis Association	www.apacure.com	Information on news, research, publications, discussion, and events related to spinal cord injury and paralysis
Electrologic of America	www.electrologic.com/index.html	Latest news about the cure for SCI
National Spinal Cord Injury Association	www.spinalcord.org	Improving care, producing results in research, and addressing everyday living issues that confront all people in wheelchairs
Spinal Cord Injury Resources	www.makoa.org/sci.htm	Links containing general resources, newsletters, articles, and fact sheets
WheelWeb.Com: The Spinal Cord Injury Resource	www.wheelweb.com	Purpose is to educate people about SCI and advance the lives of those who have it

Prader-Willi Syndrome

GeneClinics	www.geneclinics.org/profiles/	Basic information on the disorder
	pws	
PedBase	www.icondata.com/health/ pedbase/files/PRADER- W.HTM	Basic information on the disorder
Prader-Willi Syndrome	www.pwsausa.org	Information on organizations, FAQ's,
Association		research, brochures, and support

Rare Disorders

National Organiation for	www.rarediseases.org	Committed to the identification,
Rare Disorders(NORD)		treatment, and cure of rear disorders
, , ,		through programs of education,
		advocacy, research, and service;
		newsletter, and search databases
Genetic/Rare Conditions	www.kumc.edu/gec/support/	Allows for a search of support groups
Support Groups &	groups.html	according to disability; information on
Information Site	3 1	genetic conditions or birth defects for
		professionals, educators, and individuals
Rare Genetic Diseases in	Mcrcr2.med.nyu.edu/	Pathway search to specific rare
Children	murphp01/homenew.htm	disorders

Rett Syndrome

International Rett	www.rettsyndrome.org	Purpose is to support and encourage
Syndrome Association		medical research, determine the cause
		and find a cure for Rett syndrome, to
(IRSA)		increase public awareness, and to provide
		informational and emotional support to
		families; available in French, Dutch,
		I talian, Portuguese, and Spanish

Seizure Disorders

American Epilepsy	www.aesnet.org	Promotes research and education for
Society		professionals dedicated to the
		prevention, cure, and treatment of
		epilepsy
Lycoszone	Lycoszone.Lycos.com	Light-hearted website that focuses on
	Go to search and type in	epilepsy and seizure disorders for
	"epilepsy"	youngsters and teens.
Epilepsia	www.epilepsia.com	Official journal of The International
		League Against Epilepsy (on-line journal)
Epilepsy Contact	www.datasync.com/~josw/	A database of families and bookstore
Database	epilepsy.htm	developed to unite and educate those
	1 1 3	affected by and afflicted by epiliepsy
Epilepsy Foundation of	www.efa.org	Provides information on advocacy,
America		services, publications, research, etc.

Epilepsy International	www.epiworld.com	Provides a large, comprehensive and well-designed educational and informational resource for those working with and/or dealing with epilepsy on a day-to-day basis in English and Spanish language
Parent site	geocities.com/HotSprings/ 1000	Support platform for parents and other caregivers of children with epilepsy
The Epicentre	137.172.248.46/epilepsy.htm	Provides basic information & answers FAQ's

Spinal Muscular Atrophy

Families of Spinal	www.fsma.org	Provides information, resources,
Muscular Atrophy		research articles, membership
1 3		information, photos, and links
Vanderbelt Medical	www.mc.vanderbilt.edu/peds/	Vanderbelt Medical Center information
Center - SMA	pidl/neuro/spineatr.htm	on the disorder

Tourette Syndrome

The Facts about	Members.tripod.com/	A collection of general information,
Tourette Syndrome	~tourette13	FAQ's, causes, related problems, and
3		links
Guide to the Diagnosis &	www.mentalhealth.com/book/p40	Booklet intended to provide information
Treatment of Tourette	<u>-gtor.html</u>	to professionals who wish to become
Syndrome		more knowledgeable about Tourette
		Syndrome
National Tourette	www.tsa-usa.org	National organization dedicated to
Syndrome Association		providing up-to-date, accurate
		information about Tourette Syndrome
TS "Plus"	www.tourettesyndrome.net	Current research and information on TS,
		its treatment, and educational issues.
		Files for parents, educators, and health
		care professionals to download. Links to
		other resources on the net

Tuberous Sclerosis

Global TS Information	Members.aol.com/gtsil/ts/	Provides information about TS and the
Link	index.htm	organization with a bookstore,
		newsletter, and links
National Tuberous	www.tsalliance.org	Provides information about TS, the
Sclerosis Association		organization and gives resources and
		parent support

Vision Impairments

American Council of the Blind	www.acb.org	Provides general information about the Council, including recent issues of the
		monthly publication, The Braille Forum
American Foundation for	www.afb.org	National resource for people who are
the Blind	-	blind or visually impaired, and the
		organizations that serve them;
		information, newsletters, events, on-line
		journal
Art Through Touch	Members.aol.com/ATTouch	Organization that provides tuition and a
		range of high quality art activities for
		blind and visually impaired people
Association for the Blind	www.grcmc.org/blindser	Provides information, support, and tips
and Visually I mpaired		
Blind Children's Learning	www.blindkids.org	Center that seeks to develop the full
Center		potential of children and youth with a
		visual impairment, in the greater Orange
		County community, regardless of ability
		to pay
Blindness Resource	www.nyise.org/blind.htm	Provides information on resources for
Center (NYISE)		the blind
EyeNet - American	www.aao.org	Public information, resource guide, and
Academy Of		on-line education center
Ophthalmology		
Microphthalmia,	www.angelfire.com/mi/	Designed to bring families together to
Anophthalmia and other	microphthalmia	share personal stories and experiences,
Eye Disorders	·	links available
National Association for	www.navh.org	Provides a merchandise store, links,
Visually Handicapped		resources, excerpts library, and mailing
3		list
National Federation of	www.nfb.org	Comprehensive consumer and advocacy

the Blind		organization that provides public education, information and referrals
National Library Service for the Blind & Physically Handicapped (NLS)	Icweb.loc.gov/nls/nls.html	Administers a free library program of Braille and recorded materials, as well as a music program, circulated to eligible borrowers through a network of cooperating libraries
Visual Impairment Guide	www.viguide.com	Guide to internet resources about visual impairments for parents and teachers

Williams Syndrome

Williams Syndrome Association	www.williams-syndrome.org	Provides information on the disorder, medical guidelines, resource libraries, and internet links
Williams Syndrome Foundation	www.wsf.org	Provides basic information, personal stories and photos, information on organizations, and contact with families

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